



# Parents' Use of Complementary Health Approaches for Young Children with Autism Spectrum Disorder

Olivia J. Lindly<sup>1,3</sup> · Sheryl Thorburn<sup>2</sup> · Karen Heisler<sup>5</sup> · Nuri M. Reyes<sup>4</sup> · Katharine E. Zuckerman<sup>3</sup>

Published online: 14 December 2017  
© Springer Science+Business Media, LLC, part of Springer Nature 2017

## Abstract

Knowledge of why parents use complementary health approaches (CHA) for children with autism spectrum disorder (ASD) is limited. We conducted a mixed methods study to better understand factors influencing parents' decision to use CHA for ASD. Parent-reported data about CHA use were collected on a probability sample of 352 young children with ASD in Denver, Colorado; Los Angeles, California; or Portland, Oregon. Follow-back interviews were conducted with 31 parents. CHA use was negatively associated with older child age and positively associated with parents' belief ASD has major consequences, living in Portland or Denver, and medication use. Nine themes help explain these results. Study findings may have utility for healthcare providers working with children with ASD and their families regarding CHA.

**Keywords** Autism spectrum disorder · Complementary and alternative medicine · Complementary health approaches · Mixed methods research

## Introduction

Autism spectrum disorder (ASD) is a complex and chronic neurodevelopmental disorder characterized by impairment in social interaction and behavioral functioning (American Psychiatric Association 2013). ASD is often diagnosed in early childhood (Zuckerman et al. 2015), and ASD has become increasingly prevalent among children in the United States (Christensen et al. 2016) and in other countries (Baron-Cohen et al. 2009). Certain treatments, such as

early intensive behavioral intervention, are efficacious for ASD symptoms and are, therefore, often recommended by conventional healthcare providers (Myers and Johnson 2007; Weitlauf et al. 2014; Williamson et al. 2017). Yet conventionally recommended treatments typically incur costs for families, both in terms of the time and out-of-pocket expense required, and may also take time to show any noticeable and positive effects for children with ASD. By contrast, complementary health approaches (also referred to as complementary and alternative medicine [CAM]) may be perceived by parents as being more within their control to utilize and as having greater potential to show immediate and positive effects for their child with ASD (Cidav et al. 2012; Ganz 2007; Gupta 2010; Hyman and Levy 2005). Within this context, parents commonly pursue complementary health approaches for children with ASD.

Complementary health approaches (CHA) encompass a wide array of modalities developed outside of or parallel to mainstream medicine including those classified as natural products (e.g., vitamins, herbal supplements), mind and body practices (e.g., chiropractic manipulation, yoga), and other approaches (e.g., special diets, chelation therapy) (National Center for Complementary and Integrative Health, U.S. Department of Health and Human Services 2015). Parental use of CHA for children with ASD in the United States and Europe ranges from 17.3% (Zuckerman

✉ Olivia J. Lindly  
olindly@mgh.harvard.edu

<sup>1</sup> Department of General Academic Pediatrics, Massachusetts General Hospital for Children and Harvard Medical School, 125 Nashua Street, Boston, MA 02114, USA

<sup>2</sup> School of Social and Behavioral Health Sciences, College of Public Health and Human Sciences, Oregon State University, 401 Waldo Hall, Corvallis, OR 97331, USA

<sup>3</sup> Division of General Pediatrics, School of Medicine, Oregon Health & Science University, 707 SW Gaines Street, Portland, OR 97239, USA

<sup>4</sup> Department of Psychiatry, School of Medicine, University of Colorado, 13121 E. 17th Avenue, 5th Floor, Aurora, CO 80045, USA

<sup>5</sup> Childhood Health Associates of Salem, Oregon, Salem, USA

et al. 2015) to 47.0% (Salomone et al. 2015). In addition, CHA use is more common in children with ASD compared to other children, even those with other developmental disabilities (Akins et al. 2014; Valicenti-McDermott et al. 2013; Wong and Smith 2006).

ASD symptomatology (Hall and Riccio 2012; Hopf et al. 2016; Perrin et al. 2012; Salomone et al. 2015; Valicenti-McDermott et al. 2013), greater parent education (Akins et al. 2014; Hall and Riccio 2012; Hanson et al. 2007; Owen-Smith et al. 2015; Salomone et al. 2015; Wong and Smith 2006), and use of multiple health services (Akins et al. 2014; Owen-Smith et al. 2015; Salomone et al. 2015) are associated with an increased likelihood of parental CHA use for children with ASD. Discrepant findings have, however, emerged about the relationship of age, sex, and race/ethnicity with parental use of CHA for children with ASD (Akins et al. 2014; Hall and Riccio 2012; Hanson et al. 2007; Hopf et al. 2016; Levy et al. 2003; Owen-Smith et al. 2015; Perrin et al. 2012; Salomone et al. 2015; Valicenti-McDermott et al. 2013; Wong and Smith 2006; Zuckerman et al. 2015). Moreover, little research has qualitatively explored how these factors, together, contribute to parental use of CHA for children with ASD. Methodological differences (e.g., definition and measurement of CHA use and correlates) and limitations (e.g., cross-sectional design, nonprobability sampling) across past studies also further constrain understanding of *why* parents use CHA for children with ASD.

Greater knowledge of factors motivating parental use of CHA for children with ASD is needed for several reasons. First, improving understanding of parental use of CHA for children with ASD is important because it is common (Hofer et al. 2017). Second, many CHA modalities have limited evidence of efficacy and safety for treating ASD symptoms (Anagnostou and Hansen 2011; Cheuk et al. 2011; Ghanizadeh 2012; Hendren 2013; Huffman et al. 2011; James et al. 2011, 2015; Levy and Hyman 2015; Nye and Brice 2005; Whitehouse 2013; Williams et al. 2012). Third, parental use of CHA for children with ASD often incurs even greater out-of-pocket costs for families belonging to a subgroup that is already likely to experience high financial burden (Gupta 2010; Nahin et al. 2016).

For these reasons, additional research employing mixed quantitative and qualitative methods is needed to establish a more comprehensive understanding of why parents use CHA for children with ASD. This study was, therefore, intended to generate new knowledge on this topic. In specific, we aimed to: (1) identify what ecological factors at the child, family, and health system levels influence parental use of CHA for children with ASD; and (2) describe, from the parent perspective, *how* these factors may affect use of CHA for children with ASD. We adapted the Complementary

and Alternative Medicine (CAM) Healthcare Model (Fouladbaksh and Stommel 2007), which is a modification to the Behavioral Model of Health Services Utilization (Andersen 2008), as the conceptual framework to guide our study (Appendix). Based on the literature reviewed and the availability of related measures for this study, we hypothesized that greater ASD severity, higher parent education level, and higher number of health services utilized would have positive and statistically significant associations with parental use of CHA for children with ASD.

## Method

This study was added to a larger study investigating barriers to autism care for Latino and non-Latino children. We used an embedded mixed methods design (Creswell et al. 2011), in which qualitative data were used to help explain quantitative results about associations of ecological (i.e., child, family, and health system) factors associated with parents' use of CHA for children with ASD. Integration of results occurred after both quantitative and qualitative data collection and analysis were completed. The Institutional Review Boards at the affiliated universities approved the study.

## Quantitative Methods

### Survey Sampling and Participants

Probability samples of Latino and non-Latino white children aged 2–10 years with an ASD diagnosis confirmed in the past 5 years were selected from three ASD clinics in Denver, Colorado; Los Angeles, California; and Portland, Oregon. Parents of the children selected were then recruited through mailings and follow-up telephone calls. The survey sampling and recruitment procedures are detailed in a previous article (Zuckerman et al. 2017). The final survey sample included 352 children with ASD aged 2–10 years across the three sites.

At the time of the survey, the median age of children with ASD was 6 years. As shown in Table 1, most children with ASD were male, and more than half had parent-reported moderate or severe ASD. A plurality of parents reported English-speaking proficiency, always having lived in the United States, and being married or partnered. In terms of their beliefs regarding ASD, most parents agreed ASD is lifelong, challenges of ASD can be reduced with treatment, and ASD has major consequences on the child's life. On average, some stigma of ASD was perceived in the child's community, a diagnostic delay of more than a year occurred, seven or more barriers to accessing ASD care were

**Table 1** Child, Family, and Health System Factors among a Probability Sample of Children with ASD aged 2–10 years, Overall and by Any Use of Complementary Health Approaches

	Overall <sup>a</sup>	No CHA	Any CHA	No vs. any CHA OR (95% CI)
<i>N</i> (%)	352 (100%)	194 (55.1%)	158 (44.9%)	–
<b>Child level</b>				
Age, years ( <i>n</i> = 343)				
<i>M</i> ( <i>SD</i> )	6.17 (2.00)	6.33 (2.04)	5.99 (1.93)	<b>0.92 [0.82, 1.02]</b>
<i>p</i> -value		<b>0.11</b>		
Age when ASD diagnosed ( <i>n</i> = 346)				
Mean ( <i>SD</i> )	3.47 (1.42)	3.64 (1.47)	3.28 (1.35)	<b>0.83 [0.71, 0.97]</b>
<i>p</i> -value		<b>0.02</b>		
Sex ( <i>n</i> = 348)				
Male ( <i>n</i> = 291)	83.6%	56.4%	43.6%	1.00
Female ( <i>n</i> = 57)	16.4%	49.1%	50.9%	1.34 [0.76, 2.36]
<i>p</i> -value		0.32		
Health insurance coverage ( <i>n</i> = 347)				
Public health insurance only ( <i>n</i> = 210)	60.5%	53.3%	46.7%	1.00
Any private health insurance ( <i>n</i> = 137)	39.5%	56.9%	43.1%	0.86 [0.56, 1.33]
<i>p</i> -value		0.51		
Child ASD severity ( <i>n</i> = 344)				
Mild ( <i>n</i> = 162)	47.1%	64.2%	35.8%	1.00
Moderate or severe ( <i>n</i> = 182)	52.9%	47.3%	52.8%	<b>2.00 [1.30, 3.09]</b>
<i>p</i> -value		<b>0.002</b>		
<b>Family level</b>				
Family ethnicity and language ( <i>n</i> = 352)				
Non-Latino, white, English proficient ( <i>n</i> = 163)	46.3%	49.7%	50.3%	1.00
Latino, English proficient ( <i>n</i> = 95)	27.0%	57.9%	42.1%	0.72 [0.43, 1.20]
Latino, limited English proficiency ( <i>n</i> = 94)	26.7%	61.7%	38.3%	<b>0.61 [0.37, 1.03]</b>
<i>p</i> -value		<b>0.14</b>		
Children per household ( <i>n</i> = 346)				
<i>M</i> ( <i>SD</i> )	2.14 (1.09)	2.18 (1.08)	2.07 (1.10)	0.91 [0.74, 1.10]
<i>p</i> -value		0.32		
Children with ASD per household ( <i>n</i> = 342)				
Mean ( <i>SD</i> )	1.14 (0.44)	1.12 (0.43)	1.17 (0.46)	1.29 [0.79, 2.11]
<i>p</i> -value		0.3		
Parent nativity ( <i>n</i> = 352)				
Always lived in U.S. ( <i>n</i> = 228)	64.8%	53.5%	46.5%	1.00
Lived outside the U.S. ( <i>n</i> = 124)	35.2%	58.1%	41.9%	0.83 [0.53, 1.29]
<i>p</i> -value		0.41		
Family structure ( <i>n</i> = 351)				
Married or living with partner ( <i>n</i> = 278)	79.2%	55.8%	44.2%	1.00
Single ( <i>n</i> = 32)	9.1%	50.0%	50.0%	1.26 [0.61, 2.62]
Other ( <i>n</i> = 41)	11.7%	53.7%	46.3%	1.09 [0.56, 2.10]
<i>p</i> -value		0.81		
Parent education, years ( <i>n</i> = 345)				
<i>M</i> ( <i>SD</i> )	13.65 (3.91)	13.44 (4.13)	13.91 (3.62)	1.03 [0.98, 1.09]
<i>p</i> -value		0.26		
Parent employment ( <i>n</i> = 352)				
Employed ( <i>n</i> = 174)	49.4%	50.0%	50.0%	1.00
Unemployed ( <i>n</i> = 178)	50.6%	60.1%	39.9%	<b>0.66 [0.44, 1.01]</b>
<i>p</i> -value		<b>0.06</b>		

**Table 1** (continued)

	Overall <sup>a</sup>	No CHA	Any CHA	No vs. any CHA OR (95% CI)
Delay in parent concern and talking w/provider ( <i>n</i> = 343)				
<i>M</i> ( <i>SD</i> )	0.40 (0.75)	0.40 (0.73)	0.41 (0.78)	1.02 [0.77, 1.36]
<i>p</i> -value		0.87		
Belief ASD is lifelong vs. temporary ( <i>n</i> = 350)				
Disagree ( <i>n</i> = 68)	19.4%	55.4%	44.6%	1.00
Agree ( <i>n</i> = 282)	80.6%	55.0%	44.0%	0.98 [0.57, 1.66]
<i>p</i> -value		0.93		
Belief that challenges of ASD can be decreased with treatment ( <i>n</i> = 349)				
Disagree ( <i>n</i> = 35)	10.0%	57.1%	42.9%	1.00
Agree ( <i>n</i> = 314)	90.0%	54.5%	45.5%	1.12 [0.55, 2.26]
<i>p</i> -value		0.76		
Belief about having the power to change child's ASD ( <i>n</i> = 346)				
Disagree ( <i>n</i> = 182)	52.6%	58.2%	41.8%	1.00
Agree ( <i>n</i> = 164)	47.4%	51.2%	48.8%	1.33 [0.87, 2.03]
<i>p</i> -value		0.19		
Belief child's ASD is a mystery ( <i>n</i> = 347)				
Disagree ( <i>n</i> = 205)	59.1%	54.6%	45.4%	1.00
Agree ( <i>n</i> = 142)	40.9%	54.9%	45.1%	0.99 [0.64, 1.52]
<i>p</i> -value		0.96		
Being upset when thinking about child's ASD ( <i>n</i> = 345)				
Disagree ( <i>n</i> = 187)	54.2%	55.6%	44.4%	1.00
Agree ( <i>n</i> = 158)	45.8%	53.8%	46.2%	1.08 [0.70, 1.65]
<i>p</i> -value		0.74		
Belief ASD has major consequences on child's life ( <i>n</i> = 344)				
Disagree ( <i>n</i> = 97)	28.2%	68.0%	32.0%	1.00
Agree ( <i>n</i> = 247)	71.8%	49.4%	50.6%	<b>2.18 [1.33, 3.58]</b>
<i>p</i> -value		<b>0.002</b>		
Health system level				
Perceived ASD stigma ( <i>n</i> = 349)				
<i>M</i> ( <i>SD</i> )	2.31 (0.60)	2.27 (0.65)	2.37 (0.54)	<b>1.35 [0.95, 1.92]</b>
<i>p</i> -value		<b>0.09</b>		
Site ( <i>n</i> = 352)				
Los Angeles, California ( <i>n</i> = 114)	32.4%	63.2%	36.8%	1.00
Denver, Colorado ( <i>n</i> = 110)	31.3%	52.7%	47.3%	1.54 [0.90, 2.62]
Portland, Oregon ( <i>n</i> = 128)	36.4%	50.0%	50.0%	<b>1.71 [1.02, 2.87]</b>
<i>p</i> -value		<b>0.10</b>		
ASD diagnostic delay, years ( <i>n</i> = 345)				
<i>M</i> ( <i>SD</i> )	1.35 (1.19)	1.39 (1.29)	1.31 (1.06)	0.95 [0.79, 1.13]
<i>p</i> -value		0.54		
Number of barriers experienced to ASD care ( <i>n</i> = 352)				
<i>M</i> ( <i>SD</i> )	7.56 (2.70)	7.48 (2.79)	7.66 (2.59)	1.03 [0.95, 1.11]
<i>p</i> -value		0.52		
Conventional therapy services <sup>b</sup> used ( <i>n</i> = 352)				
Mean ( <i>SD</i> )	2.73 (1.44)	2.56 (1.33)	2.94 (1.55)	<b>1.20 [1.04, 1.40]</b>
<i>p</i> -value		<b>0.02</b>		
Weekly dose of therapy services ( <i>n</i> = 344)				
<1 or no hours per week ( <i>n</i> = 56)	16.3%	60.7%	39.3%	1.00
1–10 h per week ( <i>n</i> = 215)	62.5%	57.7%	42.3%	1.13 [0.62, 2.07]

**Table 1** (continued)

	Overall <sup>a</sup>	No CHA	Any CHA	No vs. any CHA OR (95% CI)
> 10 h per week ( <i>n</i> = 73)	21.2%	42.5%	57.5%	<b>2.09 [1.03, 4.26]</b>
<i>p</i> -value		<b>0.05</b>		
Receipt of special education services ( <i>n</i> = 352)				
No ( <i>n</i> = 186)	52.8%	59.7%	40.3%	1.00
Yes ( <i>n</i> = 166)	47.2%	50.0%	50.0%	<b>1.48 [0.97, 2.56]</b>
<i>p</i> -value		<b>0.07</b>		
Use of applied behavioral analysis ( <i>n</i> = 352)				
No ( <i>n</i> = 275)	78.1%	58.6%	41.5%	1.00
Yes ( <i>n</i> = 77)	21.9%	42.9%	57.1%	<b>1.88 [1.13, 3.14]</b>
<i>p</i> -value		<b>0.01</b>		
Medication use ( <i>n</i> = 352)				
No ( <i>n</i> = 263)	74.7%	61.6%	38.4%	1.00
Yes ( <i>n</i> = 89)	25.3%	36.0%	64.0%	<b>2.86 [1.73, 4.71]</b>
<i>p</i> -value		<b>&lt; 0.001</b>		
Unmet need for therapy services ( <i>n</i> = 345)				
No ( <i>n</i> = 176)	51.0%	55.1%	44.9%	1.00
Yes ( <i>n</i> = 169)	49.0%	54.4%	45.6%	1.03 [0.67, 1.57]
<i>p</i> -value		0.90		

Bolded variables had statistically significant associations at a  $p < .15$  level

Differences in distributions of binary or nominal variables by use of CHA were determined using Pearson Chi square tests, and with two-sample *t* tests adjusted for unequal variances for continuous or count variables

ASD autism spectrum disorder, CHA complementary health approaches, CI confidence interval, *M* mean, *SD* standard deviation

<sup>a</sup>Not all percentages sum to 100% due to rounding

<sup>b</sup>The following conventional treatment services for ASD were included: (speech and language therapy, social skills training, occupational therapy, psychological counseling, applied behavioral analysis, other behavioral therapy, and other therapy). Does not include any CHA

experienced, and more than two conventional therapy services were utilized for the child's ASD. Most children also received more than 1 h of therapy per week, and nearly half reported unmet need for therapy services.

### Survey Development and Administration

The survey instrument included 34 items. Whenever possible, previously used and/or validated measures were included. Measures of child and family characteristics were primarily adapted from the U.S. Census American Community Survey (U.S. Census Bureau 2015) and the 2009–2010 National Survey of Children with Special Health Care Needs (National Center for Health Statistics 2014). For instance, parent belief measures (e.g., ASD has major consequences on the child's life) were adapted from the previously validated Illness Perception Questionnaire Revised for Autism (Al Anbar et al. 2010). Measures of ASD services use were largely adapted from the 2011 Survey of Pathways to Diagnosis and Services (National Center for Health Statistics 2015). Because validated and previously used measures for certain concepts such as barriers to ASD care and ASD

stigma did not exist, new measures were developed. The initial survey instrument was refined based on feedback from Autism Parent Advisory Committees at two sites and pilot testing with 20 parents of children with ASD.

Most participants completed the survey by mail ( $n = 322$ ). For those participants who did not complete the survey by mail, but agreed to complete the survey by telephone ( $n = 30$ ), a trained interviewer administered the survey in English or Spanish. The survey was administered from March 2014 to October 2015. The survey response rate was 76.2%.

### Child, Family, and Health System Factors Examined

For this study, the conceptual framework (Appendix) guided our selection of variables indicative of factors at the child, family, or health system levels potentially associated with CHA use among children with ASD. As displayed in Table 1, child level factors included child age, age of initial ASD diagnosis, sex, health insurance coverage, and parent-reported ASD severity (i.e., mild versus moderate or severe). Family level factors included ethnicity and primary

language, number of children per household, number of children with ASD per household, parent nativity, family structure, years of parent education, parent employment, and delay between when parent was first concerned about the child's development and when the parent talked about concerns with a healthcare provider. Family level factors also included parent beliefs about ASD (i.e., ASD is life-long versus temporary, challenges of ASD can be decreased with treatment, parent has the power to change child's ASD, ASD is a mystery, parent becomes upset when thinking about child's ASD, and ASD has major consequences on the child's life). Parent belief measures were rated on a four-point Likert scale, ranging from 1 = strongly disagree to 4 = strongly agree. Due to response distributions, we subsequently dichotomized responses into disagree (i.e., strongly disagree or disagree) or agree (i.e., strongly agree or agree). Health system factors included perceived ASD stigma in the community (Zuckerman et al. 2017), study site, delay between when parent first talked with a healthcare provider about concerns regarding their child's development and initial ASD diagnosis (i.e., diagnostic delay) (Zuckerman et al. 2015), number of barriers experienced when accessing ASD care (Zuckerman et al. 2017), number of conventional therapy services used (i.e., speech and language therapy, social skills training, occupational therapy, psychological counseling, applied behavioral analysis, other behavioral therapy, other therapy), total hours of home or school therapy services the child usually received per week, special education receipt, applied behavioral analysis (ABA) use, prescription and/or over-the-counter (OTC) medication use for the child's ASD symptoms, and perceived unmet need for therapy services.

### Assessment of Complementary Health Approaches Used

In the survey, parents were asked "Does your child currently use any of these medications or treatments for his or her ASD symptoms?" If respondents indicated any of the following treatment types, the child was determined to use CHA: (1) vitamins; (2) herbal supplements; (3) dietary treatments, such as gluten-free or low sugar diet; (4) chiropractic, acupuncture, or massage therapy; (5) traditional healers; or (6) other CHA. Other CHA included equestrian, music, hydro, and sensory integration therapy.

### Analysis

We computed descriptive univariate and bivariate statistics for all variables of interest. Characteristics of CHA used were also descriptively examined. Chi square, t-tests, and odds ratios were used to examine unadjusted associations of child, family, and health system factors with CHA use. To determine a parsimonious model, we used a stepwise

model selection process in which variables initially determined to be associated with CHA use from bivariate analysis results ( $p < .15$ ) were included as independent variables in a multivariable logistic regression model (Bursac et al. 2008). The same alpha level was used to exclude variables from subsequent models. Goodness of model fit to the data was examined using the Hosmer–Lemeshow Chi square statistic and the Bayesian Information Criterion. A generalized linear mixed model was additionally fit to account for potential clustering by site; however, the correlation within each site related to CHA use did not necessitate this approach (results not shown), so the original modeling approach was retained. All quantitative analyses were performed in Stata 14.2 (StataCorp 2015).

## Qualitative Methods

### Sampling and Recruitment for Interviews

To be eligible for the qualitative component of this study, survey participants had to have indicated any use of CHA and English-speaking proficiency. Parents who met these criteria were recruited from the sites in Portland, Oregon and Denver, Colorado using an advance mailing and follow-up by telephone. Eligible parents interested in participating were re-screened over the telephone to determine if (1) their child was still diagnosed with ASD and (2) they had used CHA for their child in the past year. Of the 89 parents re-contacted, 31 agreed to participate and completed interviews.

### Interview Participants

Of the 31 parents who participated in interviews, 18 were from Portland and 13 were from Denver. A majority of participants were the mother of the child with ASD, identified as being white and non-Latino, and were employed (Table 2). In addition, all parents interviewed reported having 12 or more years of education and that they were 25 years or older. When the interviews were conducted, the median age of children with ASD was 8 years.

### Data Collection

Three trained interviewers conducted in-depth telephone interviews in English with parents from March 2016 to January 2017. All parents provided verbal informed consent prior to being interviewed. Interviews, which lasted 35–120 min, were audio recorded and then transcribed



**Table 2** Characteristics of parents interviewed and their children with ASD

	n	%
<b>Parent</b>		
Relationship to child with ASD		
Mother	29	94
Father	1	3
Grandmother	1	3
Age, years		
Median (Range)	36 (25–51)	
Ethnicity		
Non-Latino	19	61
Latino	12	39
Lived in the U.S. entire life	26	84
Years of education		
Median (Range)	14.5 (12–20)	
Currently employed at a paid job	25	81
<b>Child</b>		
Age at time of interview, years		
Median (range)	8 (6–12)	
Ethnicity		
Non-Latino	19	61
Latino	12	39
Sex		
Male	25	81
Female	6	19

Parent and child characteristics were based on the quantitative survey data gathered, unless otherwise indicated

ASD autism spectrum disorder

verbatim by a professional transcription firm. Each parent received a \$20 gift card after the interview.

### Interview Guide

The semi-structured interview guide was comprised of predominately open-ended questions and probes about parents' experiences using CHA for their child with ASD. The guide also included questions about parents' experiences disclosing CHA used to their child's healthcare provider(s), as well as ways in which they felt communication with healthcare providers about CHA could be improved for other families of children with ASD. An initial version of the interview guide was pilot tested with two parents of a child with ASD who had used CHA, and the feedback was used to revise the guide. The interview guide was further modified after the first seven interviews.

### Analysis

A directed content analysis approach, intended to validate and extend the conceptual framework and relevant past research, was used to analyze interview data (Hsieh and Shannon 2005). A coding scheme was initially generated after two authors independently reviewed transcripts from four interviews. The authors then independently coded the interview transcripts, met to discuss and resolve coding discrepancies with another author, and revised the coding scheme accordingly. This process continued until all transcripts were coded by the two authors. Elemental coding methods were primarily used including descriptive, in vivo, and structural coding (Saldaña 2013). After coding was completed, research team members met several times with a parent advocate who had used CHA for her child with ASD to extrapolate broader themes from the coded data and to identify illustrative quotes regarding factors promoting or impeding the use of CHA. Qualitative data analysis was performed in QSR NVivo 11.3.2 (QSR International Pty Ltd. 2014).

## Results

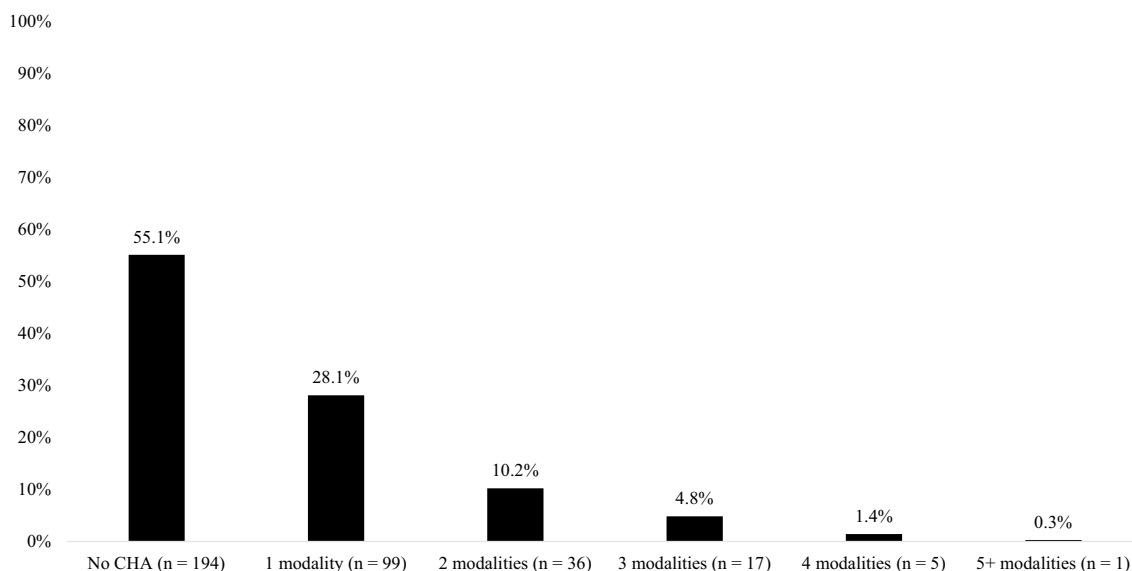
### Survey Results

Nearly half (44.9%) of children with ASD used one or more CHA. The majority used only one modality (Fig. 1). Vitamins, herbal supplements, and special diets were the most frequently used modalities (Fig. 2).

Bivariate results demonstrated statistically significant unadjusted associations of CHA use with multiple factors at the child, family, and health system levels (Table 1). Results from the final multivariable model are presented in Table 3. The only factors that retained statistically significant adjusted associations with use of CHA were child age, the belief that ASD has major consequences on the child's life, study site, and medication use. Specifically, for each year older a child with ASD was, the adjusted odds of CHA use decreased by approximately 15%. At the family level, parents who agreed ASD has major life consequences had higher adjusted odds of CHA use. At the health system level, children with ASD from Denver or Portland had higher adjusted odds of CHA use relative to children with ASD from Los Angeles. Prescription and/or over-the-OTC medication use was additionally associated with higher adjusted odds of CHA use.

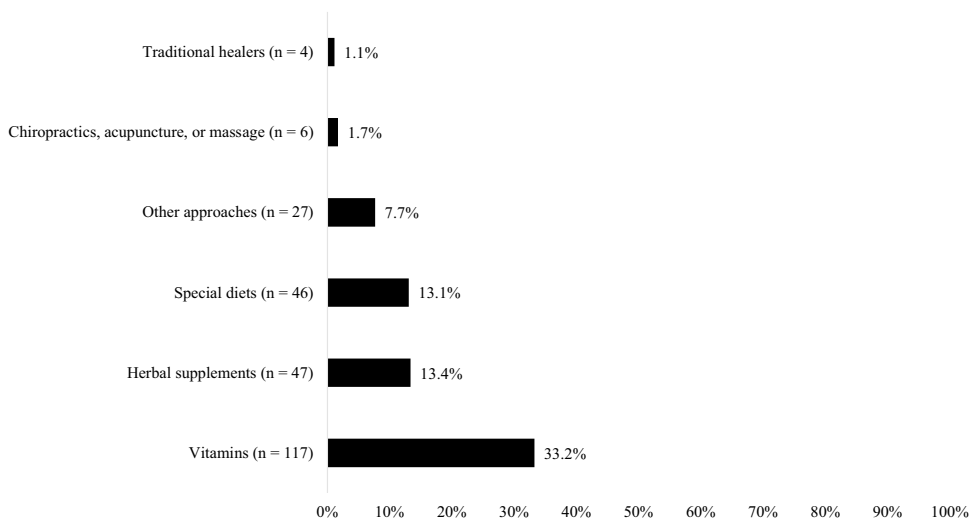
### Interview Results

Parents reported ever or currently using many different CHA for their child with ASD (Table 4). The most



**Fig. 1** Percentage of children with autism spectrum disorder aged 2–10 years who used no, one, two, three, four, or five or more complementary health approaches as reported in the survey

**Fig. 2** Type of complementary health approaches used by children with autism spectrum disorder aged 2–10 years, as reported in the survey



frequently used type of CHA was natural products (e.g., herbal supplements). Special diets, primarily gluten and/or casein free diets, was the single most frequently used modality. Massage therapy, yoga, and qigong were the most common mind and body practices used. Many parents also reported that some of the CHA used were directed by a healthcare provider (e.g., general pediatrician, naturopath). Most parents reported CHA were used with conventional healthcare; however, some reported they used CHA as an alternative to conventional healthcare. All parents reported their child with ASD used some conventional healthcare, with the most common services being preventive care (e.g., well child visits), school-based services (e.g., special education, speech and language therapy),

other therapy services (e.g., ABA), and prescription and/or OTC medication (data not shown). Thirteen parents did, however, elaborate that they used or were currently using CHA as an alternative to conventional healthcare. Most of these parents were recruited from Portland, Oregon and described CHA as an alternative to conventional healthcare (e.g., ABA) for their child's core ASD symptoms.

Nine themes emerged in relationship to the four factors significantly associated with CHA use in the final multivariable model (i.e., child age, parent belief ASD has major consequences on the child's life, study site, and medication use). For each of the four factors, relevant themes are subsequently described to provide greater



**Table 3** Final multivariable logistic regression model results (n = 351)

	aOR (95% CI): any use of CHA
<b>Child level</b>	
Age, years	0.85 [0.76, 0.96]
<i>p</i> -value	0.008
<b>Family level</b>	
Belief ASD has major consequences on the child's life	
Disagree	1.00
Agree	1.77 [1.08, 2.92]
<i>p</i> -value	0.03
<b>Health system level</b>	
Location	
Los Angeles, California	1.00
Denver, Colorado	1.99 [1.13, 2.92]
<i>p</i> -value	0.017
Portland, Oregon	2.03 [1.18, 3.50]
<i>p</i> -value	0.010
Use of medication	
No	1.00
Yes	3.27 [1.91, 5.61]
<i>p</i> -value	<0.001
Model fit	
Hosmer–Lemeshow chi2 ( <i>df</i> )	10.31 (8)
Prob > chi2	0.24

Variables that did not have a statistically significant association with use of CHA at the  $p < .15$  level in the initial multivariable model were excluded from the final model and are not included in the table  
aOR adjusted odds ratio, CHA complementary health approaches, CI confidence interval

understanding of how each factor may contribute to CHA use among children with ASD.

### The Role of Child Age

Nineteen parents discussed how their child's age had influenced their decision to use CHA. Three themes emerged in relationship to the quantitative result that the adjusted odds of CHA use decreased as age increased.

**CHA Use may be Viewed as No Longer Necessary when ASD Symptoms Change with Age** Most parents described change in their child's ASD symptomatology over time. Parents typically characterized this change as an improvement or worsening in their child's ASD symptoms. Related to CHA use, some parents described how fewer treatments including CHA were needed as their child grew older because his or her symptoms had improved or had become better managed. As one parent explained, "I mean we're doing less of [CHA]

**Table 4** Use of complementary health approaches reported by parents interviewed

	<i>n</i>	%
<b>Modalities used</b>		
Natural products overall		
Herbal or non-vitamin supplements	29	94
Herbal or non-vitamin supplements	19	61
Specific vitamins and/or minerals	18	58
Multivitamins/minerals	17	55
Essential oils	7	23
Herbal teas	3	10
Cannabis	1	3
Mind and body practices overall		
Massage therapy	25	81
Yoga	11	35
Yoga	8	26
Qigong	8	26
Meditation	6	19
Biofeedback	5	16
Music therapy	3	10
Equestrian therapy	3	10
Movement therapy	2	6
Progressive relaxation	2	6
Chiropractic or osteopathic manipulation	2	6
Skin brushing	2	6
Acupuncture	1	3
Hydrotherapy	1	3
Deep breathing exercises	1	3
Other modalities overall		
Special diets	25	81
Special diets	23	74
Naturopathy	8	26
Homeopathy	5	16
Nebulizer or Vaporizer	3	10
Chelation	2	6
Hyperbaric oxygen therapy	2	6
Books	1	3
Provider-directed use of CHA	20	65
Manner of use		
Complementary to conventional healthcare	22	71
Alternative to conventional healthcare	13	42
Integrative with conventional healthcare	10	32

Modalities were reported as being ever or currently used  
CHA complementary health approaches

now that he's getting older...I mean because some of this stuff we've either tackled it or he's grown out of it..."

By contrast, parents described CHA as less effective relative to certain conventional treatment options when their child's ASD symptoms—particularly externalizing behaviors—became more severe with age. Psychotropic medication (e.g., stimulant medication) was generally described as the form of conventional treatment with the greatest potential for adverse side effects. Still, several parents explained

the necessity of moving from solely using CHA to using CHA in combination with psychotropic medication to manage worsening symptoms as their child aged. For example, one parent said:

When he started getting bigger and older...to the point where it was a little bit harder for me to handle it from a physical standpoint. And, the alternative medicines weren't exactly working to the degree that I hoped they would be. We started turning more towards the conventional medication to control behaviors.

**There is a Perceived Critical Period to Act by Using CHA when Children with ASD are Young** In discussing the influence of their child's age on CHA use, several parents described how, once their child was diagnosed with ASD, they had a finite period to promote their child's healthy development. Parents commonly described this period as occurring in early childhood. Related to this belief, parents often recounted their tireless search for ASD treatment options to aide their child. For many, this process led them to use CHA. As one parent explained,

I felt like I was in a race sometimes to get him to make progress before he reached six years old. I don't know how accurate that statistic is, but I heard it from multiple people and sources. That had an impact on me. I don't think we rushed any treatment because of that, but I was real anxious for him to [make] progress.

**CHA are Viewed as Safe for Young Children** Most parents described how they believed CHA were safe or safer than conventional healthcare treatments available for ASD, particularly medication. In relationship to their child's age, some parents further explained how their perceived safety of CHA was a determining factor in their decision to use it for their child because their child was young and was, therefore, more susceptible to adverse health impacts. This theme is illustrated in the following exchange:

Interviewer: Did [child's] age influence your use of complementary and alternative medicine for him at all?

Parent: Probably. He was four, five, and six, and the thought of medication or ABA or other kinds of therapy seemed scarier, I guess, because he seemed so young and more fragile, perhaps.

### **The Role of Believing That ASD has Major Consequences on the Child's Life**

Three themes related to the relationship between the belief ASD has major consequences on the child's life and CHA use were identified.

**Parents can Reduce the Impact of ASD on Their Child's Life by Using CHA** Twenty-three parents described how they were initially compelled to use CHA for their child because they wanted to ameliorate their child's ASD symptoms or, in a few cases, completely cure their child's ASD. For example, one parent shared:

Qigong was just something that came about during the timeframe that my daughter still was non-verbal and had been diagnosed already. I said, "Well, what else could we do to help her? I want to get her everything I can." That was an option.

**Conventional Healthcare is Viewed as Ineffective for ASD** Twenty-five parents expressed concerns about the efficacy and/or safety (i.e., effectiveness) of conventional healthcare to treat their child's ASD. For some parents these concerns were based on their past experiences using conventional healthcare, while for others their concerns were hypothetical. Regardless, parents' perceptions that conventional healthcare is ineffective for ASD was often ascribed to their decision to use CHA, as illustrated in the following quote:

I think I've sought [CHA] out more because it—traditional medicine—does not have any options for autism specifically. They tend to throw a lot at you that's very generic....I mean, it's basically just anti-depressants and anti-anxiety medication that's used to treat a lot of stuff that has nothing to do with autism. I mean, although anxiety is a component of autism, a kid that totally doesn't have autism is using the same medication that they're treating a lot of kids with [who have] autism. So, I don't really think that the medical community—because they don't have the research and knowledge yet to do so, really offers a lot of interventions that are [effective]. I mean, behavioral, yes. Therapy, yes. But in terms of true medical medicinal options, they really... offer you very little. In that way, it steers people more towards alternative medicines because those at least seem like they are addressing the symptoms of autism more directly. For instance, a probiotic with gut inflammation. I do think there's something to that. While I don't think it's the entire key, or they would've already cured autism, I definitely think it is a component that has to be considered.

**CHA are Viewed as Effective for ASD** Twenty-nine parents described how they used CHA for their child with ASD because they believed it could improve or had improved their child's ASD symptoms. For some parents, the effectiveness of CHA for their child's ASD symptoms was described relative to their experiences with conventional healthcare. One parent described the preference for CHA in this way:

[N]obody could help us and nobody knew where to send us. The pediatrician didn't. They just wanted to keep giving him shots and I didn't want to do that because I believe that's what made him sick in the beginning. And so, then when we saw [a naturopath] and started seeing results with [CHA], and I didn't want to medicate him either. That scared me because I didn't want to create dependency. I wanted to fix the problem. I believe that now with everything, there's a root cause of everything and I want to fix the root. I don't want to stick a medicine band aid over the symptoms, I want to fix the root and heal him.

### The Role of Geographic Location

Quantitative results showed children with ASD from Denver, Colorado or Portland, Oregon had higher adjusted odds of using CHA than those from Los Angeles, California. All parents interviewed mentioned how where they lived had facilitated their use of CHA. Two key themes emerged around this topic.

**CHA is Widely Accepted in the Family's Community, Which Facilitates Use** When asked if their family's use of CHA was similar or different from the use of CHA in their community, many parents discussed how it was difficult to compare but that they generally thought their use of CHA was similar or less than use by others in their community. Most parents made these comparisons between themselves and other family members, co-workers, or other parents of children with ASD whom they associated with through support groups or educational classes. Often parents anchored these comparisons to where they currently lived; however, some parents compared the acceptability of CHA where they currently lived to places they had previously lived or visited.

I think [our use of CHA] is frankly to a minimum compared to where we live [...]. I see a lot of my neighbors, and we have a couple of families around us that do a lot of alternative medicine. We live close to [city name], so I don't know if that matters. But I almost feel like, you know, they're a little more holistic.

**CHA Accessibility in Certain Geographic Locations Makes Use Easy** Many parents also described how being easily able to access CHA in their community had facilitated use of CHA for their child with ASD. As one parent surmised: "We have easy access in [location name]. There's all sorts of places."

### The Role of Medication Use

Regarding the quantitative result that medication use was associated with greater use of CHA, the following

theme emerged: ASD may necessitate multiple treatment approaches, including the concurrent use of medication and CHA. Although many parents discussed how they opted for more "natural" CHA instead of certain conventional health-care, particularly medication, 16 parents reported using medication for their child with ASD. Some parents described how medication was or might be necessary for optimizing their child's health; however, parents often couched this by elaborating that medication is their last resort for treatment. As one parent described,

My philosophy is basically to try to treat it naturally, in a more natural way first, especially if it's something small like that. You don't just go to a pill right away that may have side effects and other problems that come with it. You try to treat it naturally first. But then if it's a huge problem and if it's something that needs more traditional work, then fine we do that, but my philosophy is you try something else first and I feel like that's been good for him.

## Discussion

Our study's findings provide new knowledge of why parents use CHA for children with ASD. This study is novel in that it is one of the first to show what and how different ecological factors at the child, family, and health system levels may influence parents' use of CHA among young children with ASD. Past research on this topic has generally relied on quantitative methodology, primarily cross-sectional surveys of nonprobability parent samples (Christon et al. 2010; Hall and Riccio 2012; Hanson et al. 2007; Harrington et al. 2006; Hopf et al. 2016; Huang et al. 2013; Owen-Smith et al. 2015; Perrin et al. 2012; Valicenti-McDermott et al. 2013; Wong and Smith 2006). By using qualitative results to help explain quantitative results, this study's findings contribute unique insights into why many parents use CHA for children with ASD.

Contrary to our hypotheses, which did not specify age would be correlated with use of CHA, study results demonstrated that parent use of CHA was more likely when children with ASD were younger. This finding aligns with some (Owen-Smith et al. 2015) but not all past research (Perrin et al. 2012; Valicenti-McDermott et al. 2013; Wong and Smith 2006; Wong 2009; Zuckerman et al. 2015). Most studies have not shown a statistically significant association between age and use of CHA for children with ASD. Past research showing use of CHA is more likely in younger children with ASD than older children with ASD suggests older children may not want to use CHA and/or their parents may turn to other therapies after trying CHA when the child was first diagnosed with ASD (Owen-Smith et al. 2015). Our study's qualitative findings

lend some support for the latter explanation because many parents interviewed described the cyclical nature of trying different treatments over time for their child with ASD. Parents described this cycle primarily in relationship to changes in their child's ASD symptoms, as well as feeling compelled to use CHA when children were younger to promote their healthy development and minimize health risks and because they viewed CHA as being relatively safe. Several parents who were interviewed did describe the ease of using CHA as decreasing with child age; however, this decrease in use was mainly regarding certain mind and body practices (e.g., qigong, massage therapy) rather than natural products (e.g., vitamins) or other approaches (e.g., special diets). To more fully understand how ease of use and the child's treatment preferences contribute to use of CHA, additional research capturing the perspectives of children with ASD using CHA is needed.

Past research shows parents of children with greater ASD severity or medical complexity (e.g., comorbid gastrointestinal problems, hyperactivity) (Hall and Riccio 2012; Perrin et al. 2012; Salomone et al. 2015; Valicenti-McDermott et al. 2013) are more likely to use CHA for their child. We accordingly hypothesized that parent-reported ASD severity (i.e., mild vs. moderate or severe) would be associated with use of CHA; however, our study's results did not show a statistically significant association of parent-reported ASD severity with CHA use. Rather parents' belief that ASD has major consequences on the child's life—a variable not examined in prior research on CHA use—was associated with being more likely to use CHA. Parent perceptions of their child's ASD severity are related to ASD's impact on their family (Zablotsky et al. 2015). For this reason, the belief that ASD has major consequences on the child's life may be more salient to parents than the somewhat arbitrary rating of ASD as being mild, moderate or severe. Therefore, this belief may also be more predictive of CHA use than ASD severity or medical complexity. Our qualitative findings further illuminate that parents may believe they can reduce ASD's impact on their child's life by using CHA, and relatedly, that they view CHA as being effective and conventional healthcare as being ineffective for treating ASD. Past research shows that parents commonly view CHA as efficacious for treating ASD (Christon et al. 2010; Hopf et al. 2016; Huang et al. 2013; Wong and Smith 2006). Future research is, however, needed to determine how parents' evolving beliefs regarding their child's ASD in addition to their perceptions of the relative effectiveness of CHA and routinely recommended conventional therapies for their child's ASD may influence parents' decisions to continue or cease the use of CHA for their child over time. In addition, future research should examine how parent views regarding the safety of CHA (e.g., "it is natural"), as part of its effectiveness, are formed and what can be done

to correct any erroneous views of safety that parents may have for potentially harmful modalities (e.g., chelation and hyperbaric oxygen therapy).

Little research has examined how place may affect parents' use of CHA for children with ASD. One study did find U.S. school-aged children with ASD in the South were less likely than those in the West to use CHA (Zuckerman et al. 2015). Our study showed parents of children with ASD in Denver or Portland may be more likely to use CHA for their child than those in Los Angeles. Qualitative findings suggest that the acceptability and accessibility of CHA in the family's geographic location may contribute to such variation. Future research should determine how geography including rurality may deter parents' use of CHA for their child's ASD.

Our study's finding that parents' use of CHA is more likely for children with ASD who also use medication is consistent with some past research (Owen-Smith et al. 2015; Salomone et al. 2015) and lends some support for our hypothesis that higher services use is correlated with use of CHA. Earlier investigations have, indeed, suggested certain prescription medications (e.g., risperidone) may be efficacious for treating core and associated ASD symptoms (Huffman et al. 2011). Still, as demonstrated by our qualitative findings, parents may be reluctant to pursue medication—particularly psychotropic medication—until they have exhausted other treatment options they view as "safer." That is, parents' willingness to use medication may increase when they do not see improvement in their child's ASD symptoms or when symptoms become more severe while using other treatment options. In this scenario, medication use may also reflect greater ASD severity or medical complexity, for which continued use and/or concurrent use of CHA may be viewed as necessary by parents in their efforts to optimize their child's health.

Unlike past research (Akins et al. 2014; Hall and Riccio 2012; Hanson et al. 2007; Owen-Smith et al. 2015; Salomone et al. 2015; Wong and Smith 2006), our study's results did not show a statistically significant association of parent education with use of CHA for their child's ASD. This may be due in part to how education was measured in the survey (i.e., years of education rather than receipt of terminal degrees such as a high school diploma were asked about). In addition, the study sample surveyed was relatively homogeneous in terms of having an average of 13 or more years of education. Another plausible explanation is that education could have less bearing on parents' awareness of CHA and their decision to use it because information about CHA has become more widely accessible through sources like the Internet and CHA is more broadly available.

## Limitations

This study has important limitations. First, we cannot generalize the quantitative results beyond the population from

which the study sample was drawn. Nevertheless, probability sampling was used for the survey, and the survey sample included children who each had a verified ASD diagnosis. Much of the relevant past research has used nonprobability sampling and has not confirmed child ASD status. Also, regarding our study's quantitative component, post-hoc analysis results suggest that the use of CHA for ASD may have been reported to a lesser extent among most parents who completed the survey by mail versus the minority of parents who completed the survey by telephone. For this reason, additional research is needed to better understand parents' reporting biases about the use of CHA for children with ASD in relation to data collection mode and may be useful to best facilitate accurate reporting in future studies. Because we were only able to recruit parents from Denver or Portland for interviews, our qualitative findings are even more limited with respect to generalizability. Moreover, interviews were conducted with a purposive sample of parents who used CHA for their child with ASD, and consequently perspectives of those who were not recruited (e.g., parents who were unreachable, parents who did not elect to use CHA for their child with ASD) were not captured. Because the survey was not originally intended to focus on CHA, it did not measure certain factors such as household income that have been correlated with use of CHA in previous research. Relatedly, in the survey, parents may have reported CHA used for their child's ASD that was medically indicated (e.g., iron or vitamin D supplementation). For this reason, estimates of CHA use from the survey data may have been biased because it was not possible to determine if the various modalities reported were medically indicated or were considered by parents to be CHA. All interviews were conducted by telephone to maximize the convenience of participation for parents; however, this mode of data collection could have reduced the comfort level and/or rapport between the interviewer and participants. More broadly, this study only included data from parents of children with ASD, an important but singular information source. Consequently, further research is needed to elucidate the mechanism through which use of CHA occurs for ASD by incorporating child and provider perspectives.

## Conclusions

Findings from our mixed methods study show that parents' decision to use CHA for their child with ASD is often multifactorial. Quantitative study results demonstrate child age, parent beliefs about the consequences of ASD for their child's life, geographic location, and medication use are each associated with parents' use of CHA for their child's ASD. Qualitative study results provide further insights into why and how these factors contribute to parents' use of CHA for children with ASD. Parents generally have the best intentions

when deciding to use CHA for their child with ASD, that is, to optimize the child's health. Yet these intentions may be misinformed contributing to the use of ineffective, unsafe, and/or costly CHA for children with ASD, in some cases at the exclusion of potentially efficacious behavioral or educational interventions for ASD. Efforts to increase parents' understanding of viable ASD treatment options and resources during or directly following the diagnostic process may enable parents to make better informed treatment decisions, which may include the use of CHA, for their child. Ensuring that conventional healthcare providers understand the context within which families often make treatment decisions for a child's ASD, and more specifically the factors likely to influence a parent's use of CHA for their child with ASD, may also help families and providers better partner in optimizing the treatment for and health of children with ASD.

**Acknowledgments** This study was supported by the Agency for Healthcare Research and Quality Grant # 5T32HS000063-24, by the Ruth Warnke Graduate Fellowship from Oregon State University, and by the National Institute of Mental Health Grant # K23MH095828. We thank Lorraine Ball, Adam Branscum, Joseph Catania, Kari-Lyn Sakuma, and Emily Ho for their feedback on the research reported. We also thank Ann Reynolds and Kathryn Smith for their assistance with the submission of research protocol materials to their respective Institutional Review Boards.

**Author Contributions** OJL conceived of and designed the study; had primary responsibility for collection, management, and analysis of the qualitative data; managed and analyzed all quantitative data used; interpreted the findings; and drafted the initial manuscript. ST was OJL's dissertation chair. In this capacity, ST participated in the design of the study, interpretation of findings, and revision of the manuscript. KEZ was one of OJL's committee members. KEZ designed and obtained funding for the parent study to which this study was added. In addition, KEZ participated in the design of the study, collection of qualitative data, interpretation of findings, and revision of the manuscript. KH participated in coding the qualitative data, interpretation of findings, and revision of the manuscript. NMR participated in collection of the qualitative and quantitative data and revision of the manuscript. All authors approved the final version.

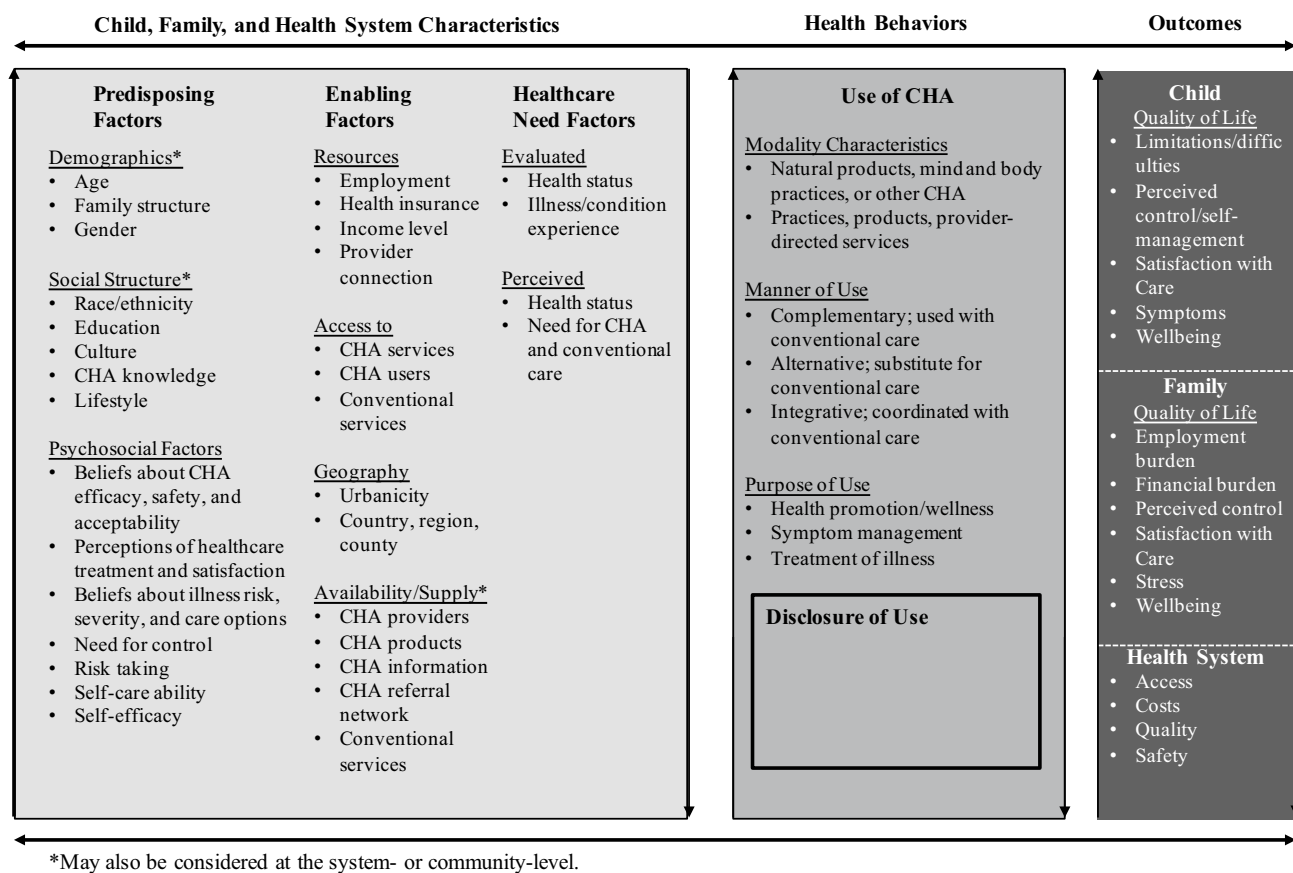
## Compliance with Ethical Standards

**Conflict of interest** All authors declare they have no conflicts of interest.

**Ethical Approval** All procedures performed in the study involving human participants were in accordance with the ethical standards of the institutional committees and with the 1964 Helsinki declaration and its later amendments.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

## Appendix



Conceptual framework. (Adapted from Fouladbakhsh and Stommel 2007)

## References

- Akins, C. R. S., Krakowiak, P., Angkustsiri, K., Hertz-Picciotto, I., & Hansen, R. L. (2014). Utilization patterns of conventional and complementary/alternative treatments in children with autism spectrum disorders and developmental disabilities in a population-based study. *Journal of Developmental and Behavioral Pediatrics*, 35(1), 1–10.
- Al Anbar, N. N., Dardennes, R. M., Prado-Netto, A., Kaye, K., & Contejean, Y. (2010). Treatment choices in autism spectrum disorder: The role of parental illness perceptions. *Research in Developmental Disabilities*, 31, 817–828.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th edn.). Arlington, VA: American Psychiatric Association.
- Anagnostou, E., & Hansen, R. (2011). Medical treatment overview: Traditional and novel psychopharmacological and complementary and alternative medications. *Current Opinion in Pediatrics*, 23, 621–627.
- Andersen, R. (2008). National health surveys and the behavioral model of health services use. *Medical Care*, 46, 647–653.
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Mathews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry*, 194(6), 500–509. <https://doi.org/10.1192/bjp.bp.108.059345>.
- Bursac, Z., Gauss, C. H., Williams, D. K., & Hosmer, D. W. (2008). Purposeful selection of variables in logistic regression. *Source Code for Biology and Medicine*, 3, 17.
- Cheuk, D. K. L., Wong, V., & Chen, W. X. (2011). Acupuncture for autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD007849.pub2>.
- Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., & Constantino, J. N. ... Centers for Disease Control and Prevention (CDC). (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *Morbidity and Mortality Weekly Report*, 65(3), 1–23.
- Christon, L. M., Mackintosh, V. H., & Myers, B. J. (2010). Use of complementary and alternative medicine (CAM) treatments by parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 4, 249–259.
- Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, 129(4), 617–623.
- Creswell, J. W., Klassen, A. C., Clark, V. L. P., & Smith, K. C. (2011). *Best practices for mixed methods research in the health sciences*. National Institutes of Health: Office of Behavioral and Social Sciences Research. Retrieved from [http://obssr.od.nih.gov/mixed\\_methods\\_research](http://obssr.od.nih.gov/mixed_methods_research).
- Fouladbakhsh, J. M., & Stommel, M. (2007). Using the behavioral model for complementary and alternative medicine: The CAM



- healthcare model. *Journal of Complementary and Integrative Medicine*. <https://doi.org/10.2202/1553-3840.1035>.
- Ganz, M. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*, *161*(4), 343–349.
- Ghanizadeh, A. (2012). Hyperbaric oxygen therapy for treatment of children with autism: A systematic review of randomized trials. *Medical Gas Research*, *2*, 13.
- Gupta, V. B. (2010). Communicating with parents of children with autism about vaccines and complementary and alternative approaches. *Journal of Developmental and Behavioral Pediatrics*, *31*, 343–345.
- Hall, S. E., & Riccio, C. A. (2012). Complementary and alternative treatment use for autism spectrum disorders. *Complementary Therapies in Clinical Practice*, *18*, 159–163.
- Hanson, E., Kalish, L. A., Bunce, E., Curtis, C., McDaniel, S., Ware, J., & Petry, J. (2007). Use of complementary and alternative medicine among children diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *37*, 628–636.
- Harrington, J. W., Rosen, L., & Garnecho, A. (2006). Parental perceptions and use of complementary and alternative medicine practices for children with autistic spectrum disorders in private practice. *Journal of Developmental and Behavioral Pediatrics*, *27*(2), 156–161.
- Hendren, R. L. (2013). Autism: Biomedical complementary treatment approaches. *Child and Adolescent Psychiatric Clinics of North America*, *22*, 443–456.
- Hofer, J., Hoffman, F., & Bachman, C. (2017). Use of complementary and alternative medicine in children and adolescents with autism spectrum disorder: A systematic review. *Autism*, *21*(4), 387–402.
- Hopf, K. P., Madren, E., & Santianni, K. A. (2016). Use and perceived effectiveness of complementary and alternative medicine to treat and manage the symptoms of autism in children: A survey of parents in a community population. *Journal of Alternative and Complementary Medicine*, *22*(1), 25–32. <https://doi.org/10.1089/acm.2015.0163>.
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288.
- Huang, A., Seshadri, K., Matthews, T. A., & Ostfield, B. M. (2013). Parental perspectives on use, benefits, and physician knowledge of complementary and alternative medicine in children with autistic disorder and attention-deficit/hyperactivity disorder. *The Journal of Alternative and Complementary Medicine*, *19*(9), 746–750.
- Huffman, L. C., Sutcliffe, T. L., Tanner, I. S. D., & Feldman, H. M. (2011). Management of symptoms in children with autism spectrum disorders: a comprehensive review of pharmacologic and complementary-alternative medicine treatments. *Journal of Developmental and Behavioral Pediatrics*, *32*, 56–68.
- Hyman, S. L., & Levy, S. E. (2005). Introduction: Novel therapies in developmental disabilities—hope, reason, and evidence. *Mental Retardation and Developmental Disabilities*, *11*, 107–109.
- James, S., Montgomery, P., & Williams, K. (2011). Omega-3 fatty acids supplementation for autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD007992.pub2>.
- James, S., Stevenson, S. W., Silove, N., & Williams, K. (2015). Chelation for autism spectrum disorder (ASD). *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD010766>.
- Levy, S., & Hyman, S. (2015). Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America*, *24*(1), 117–143.
- Levy, S., Mandell, D. S., Merhar, S., Ittenbach, R. F., & Pinto-Martin, J. (2003). Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*, *24*, 418–423.
- Myers, S. M., & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics*, *120*(5), 1162–1182.
- Nahin, R. L., Barnes, P. M., & Stussman, B. J. (2016). *Expenditures on complementary health approaches: United States, 2012 (National Health Statistics Report No. 95)* (pp. 1–11). Hyattsville: National Center for Health Statistics.
- National Center for Complementary and Integrative Health, U.S. Department of Health and Human Services. (2015). CAM Basics. Retrieved from [https://nccih.nih.gov/sites/nccam.nih.gov/files/CAM\\_Basics\\_Whats\\_In\\_A\\_Name\\_03-26-2015.pdf](https://nccih.nih.gov/sites/nccam.nih.gov/files/CAM_Basics_Whats_In_A_Name_03-26-2015.pdf).
- National Center for Health Statistics. (2014). 2009–10 National Survey of Children with Special Health Care Needs. Retrieved January 13, 2017, from <https://www.cdc.gov/nchs/slaits/cshcn.htm>.
- National Center for Health Statistics. (2015). Survey of Pathways to Diagnosis and Services. Retrieved January 13, 2017, from <http://www.cdc.gov/nchs/slaits/spds.htm>.
- Nye, C., & Brice, A. (2005). Combined vitamin B6-magnesium treatment in autism spectrum disorder. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD003497.pub2>.
- Owen-Smith, A. A., Bent, S., Lynch, F. L., Coleman, K. J., Pearson, K. A., Massolo, M. L., ... Croen, L. A. (2015). Prevalence and predictors of complementary and alternative medicine use in a large insured sample of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *17*, 40–51. <https://doi.org/10.1016/j.rasd.2015.05.002>.
- Perrin, J. M., Coury, D. L., Hyman, S. L., Cole, L., Reynolds, A. M., & Clemons, T. (2012). Complementary and alternative medicine use in a large pediatric autism sample. *Pediatrics*, *130*, S77–S82.
- QSR International Pty Ltd. (2014). NVivo qualitative data analysis software (Version 10).
- Saldaña, J. (2013). *The coding manual for qualitative researchers* (2nd edn.). Thousand Oaks, CA: SAGE Publications, Inc.
- Salomone, E., Charman, T., McConachie, H., & Warreyn, P. (2015). Prevalence and correlates of use of complementary and alternative medicine in children with autism spectrum disorder in Europe. *European Journal of Pediatrics*. <https://doi.org/10.1007/s00431-015-2531-7>
- StataCorp. (2015). *Stata Statistical Software: Release 14*. College Station, TX.
- US Census Bureau. (2015). US Census American Community Survey. Retrieved January 13, 2017, from <https://www.census.gov/programs-surveys/acs/>.
- Valicenti-McDermott, M., Burrows, B., Bernstein, L., Hottinger, K., Lawson, K., Seijo, R., ... Shinnar, S. (2013). Use of complementary and alternative medicine in children with autism and other developmental disabilities: Associations with ethnicity, child comorbid Symptoms, and parental stress. *Journal of Child Neurology*, *29*(3), 360–367.
- Weitlauf, A. S., McPheeters, M. L., Peters, B., Sathe, N., Travis, R., Aiello, R., ... Warren, Z. (2014). *Therapies for children with autism spectrum disorder: Behavioral interventions update (Comparative Effectiveness Review No. 137)*. Vanderbilt Evidence-based Practice Center. Retrieved from <http://www.effectivehealthcare.ahrq.gov/reports/final.cfm>.
- Whitehouse, A. J. (2013). Complementary and alternative medicine for autism spectrum disorders: Rationale, safety and efficacy. *Journal of Paediatrics and Child Health*, *49*, E438–E442.
- Williams, K. W., Wray, J. J., & Wheeler, D. M. (2012). Intravenous secretin for autism spectrum disorder. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD003495.pub3>.
- Williamson, E., Sathe, N., Andrews, J. C., Krishnaswami, S., McPheeters, M. L., Fonnesebeck, C., ... Warren, Z. (2017).



- Medical therapies for children with autism spectrum disorder—an update* (Comparative Effectiveness Review No. 189). Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from <http://www.effectivehealthcare.ahrq.gov/reports/final.cfm>.
- Wong, H., & Smith, R. G. (2006). Patterns of complementary and alternative medical therapy use in children diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *36*(7), 901–909.
- Wong, V. C. N. (2009). Use of complementary and alternative medicine (CAM) in autism spectrum disorder (ASD): Comparison of Chinese and Western culture (Part A). *Journal of Autism and Developmental Disorders*, *39*, 454–463.
- Zablotsky, B., Bramlett, M. D., & Blumberg, S. J. (2015). Factors associated with parental ratings of condition severity for children with autism spectrum disorder. *Disability and Health Journal*. <https://doi.org/10.1016/j.dhjo.2015.03.006>.
- Zuckerman, K. E., Lindly, O., & Sinche, B. (2015). Parent developmental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *The Journal of Pediatrics*, *166*(6), 1431–1439. <https://doi.org/10.1016/j.jpeds.2015.03.007>.
- Zuckerman, K. E., Lindly, O. J., Reyes, N., Chavez, A. E., Macias, K., Cobian, M., ... Smith, K. (2017). Family perceptions of community autism spectrum disorder stigma: measure validation and ecological associations.
- Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in diagnosis and treatment of autism in Latino and non-Latino white families. *Pediatrics*. <https://doi.org/10.1542/peds.2016-3010>.
- Zuckerman, K. E., Lindly, O. J., Sinche, B. K., & Nicolaidis, C. (2015). Parent health beliefs, child health services utilization, and child health care quality among US children with autism and other developmental conditions. *Journal of Developmental and Behavioral Pediatrics*, *36*(3), 146–157.